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## **Generalist and specialist palliative care for patients with non-malignant respiratory disease: an all-Ireland qualitative study**

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## **IAPC Annual Education and Research Seminar 2018**

**TITLE:** Generalist and specialist palliative care for patients with non-malignant respiratory disease: an all-Ireland qualitative study

### **Abstract**

**Background:** Previous research and key guidelines have suggested potential models of palliative care for patients with COPD and interstitial lung disease. However, these recommendations are often not effectively implemented in clinical practice and are void of guidance regarding palliative care for patients with bronchiectasis, another form of non-malignant respiratory disease. The aim of this research was to explore generalist and specialist palliative care service provision for people with non-malignant respiratory disease and their bereaved carers in the North and Republic of Ireland.

**Methods:** Qualitative study involving a convenience sample of 17 bereaved carers and 18 healthcare professionals recruited from a rural and urban site in Northern Ireland, and a rural and urban site in the Republic of Ireland. Data collection consisted of semi-structured interviews with carers of patients with COPD, interstitial lung disease or bronchiectasis who had died 3-18 months previously; and 4 focus groups with healthcare professionals. Data were analysed using thematic analysis.

**Results:** Findings highlighted the lack of a clear model of holistic care delivery for patients with non-malignant respiratory disease and illuminated the varying levels of palliative care provision this client group experienced. Additionally, ambiguity amongst healthcare professionals regarding prognostication illuminated the importance of the provision of palliative care being based on patient need, not prognosis. This research developed a potential model of palliative care which may help healthcare professionals introduce palliative care, and specialist respiratory care, early in the disease trajectory of non-malignant respiratory disease, whilst also encouraging the involvement of specialist palliative care for complex symptom management.

**Conclusion:** This research provides an important insight into a potential model of palliative care for people with non-malignant respiratory disease, inclusive of bronchiectasis, which incorporates palliative care in a responsive and dynamic way. However, the feasibility of integrating this model into clinical practice requires further exploration.